

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

SUMMER 2018

Raleigh Festival & 5K Walk: Join in the Fun for a Great Cause!



JADEN'S JEWELS & JADEN'S GENTS: We walk because we are family, we care, we share, and we work together in love!



WONDERFULLY MADE: We walk for Hayden and Declan, who are Wonderfully Made.



SOUTH COWS: We walk because this organization has given so much to our family over the years and this is our way of giving back.



CLOT HOPPERS: celebrating another great year at the HNC Family Festival & Walk.

The HNC Family Festival & 5K Walk for Bleeding Disorders isn't just a fundraiser. It's a day of family-oriented fun that builds and strengthens the community of people affected by bleeding disorders in North Carolina while also raising critical funds for Hemophilia of North Carolina's (HNC) programs and services. It's also a way for the community to give back. We hope you'll participate and make 2018 the biggest event yet! Save the date: September 15, 2018.

Some of our top teams from the 2017 Raleigh HNC Family Festival will be back again in 2018, so mark your calendar and come out to Morrisville to meet HNC members from throughout the state at HNC's largest event of the year.

Taking place on September 15 at Lake Crabtree Park in Morrisville, the 2018 Family Festival & Walk has a lot in store for you and your family. Great food, music, games, crafts, and more will be on hand for all to enjoy. Visit the HNC website to register as a participant or volunteer, form your walk team, and start fundraising today!



TEAM LIAM: We walk for the sweetest little boy we know: our son. He is reason enough to do anything. We walk for everyone touched by a bleeding disorder and hope through the awareness and funds we raise we can help our son and others lead an easier and exciting life.

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Save The Date

Men's Retreat

July 20-22
Blowing Rock, NC

Educational Dinner

July 24
Greenville, NC

NHF Inhibitor Education Summit

July 26-29
New Orleans, LA

Latin Union Retreat

July 28-29
Winston-Salem, NC

Educational Dinner

August 14
Charlotte, NC

NHF Inhibitor Education Summit

August 16-19
San Diego, CA

Family Day Out

August 19
Clemmons, NC

Educational Dinner

August 23
Raleigh, NC

Family Festival & 5K Walk for Bleeding Disorders

September 15
Morrisville, NC

Gettin' in the Game JNC

September 28-30
Phoenix, AZ

Blood Brotherhood Event

September 29
Lumberton, NC

NHF Bleeding Disorders Conference

October 10-13
Orlando, FL

HNC Family Retreat

October 19-21
Concord, NC



*Hemophilia of
North Carolina*

260 Town Hall Dr., Suite A
Morrisville, NC 27560
(800) 990-5557
info@hemophilia-nc.org
www.hemophilia-nc.org

MISSION STATEMENT

Hemophilia of North Carolina is a non-profit organization dedicated to improving the quality of life of persons affected by bleeding disorders through advocacy, education, promotion of research, and delivery of supportive programs and services.

Contact Numbers

Hemophilia of North Carolina

(800) 990-5557
(919) 319-0014
(919) 319-0016 (fax)

National Hemophilia Foundation

(800) 42-HANDI
www.hemophilia.org

Hemophilia Federation of America

(800) 230-9797
www.hemophiliafed.org

Community Health Charities of NC

(919) 554-3272 (Collect)
www.healthcharities.org

About This Publication

THE CONCENTRATE is the official newsletter for Hemophilia of North Carolina. It is produced quarterly and distributed free of charge to requesting members of the bleeding disorder community.

An electronic version may be found on the HNC website. If you would prefer not to receive a mailed copy of our newsletter, please contact the HNC office.

We maintain a membership mailing list. However, we never release any personal information without your permission.

Hemophilia of North Carolina does not endorse any specific products or services and always recommends that you consult your physician or local treatment center before pursuing any course of treatment.

Hemophilia Treatment Centers

East Carolina University Brody School of Medicine

600 Moye Boulevard
Pediatric Hematology/Oncology
MA Suite 333
Greenville, NC 27834
Phone: (252) 744-4676
Fax: (252) 744-8199

St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital Hematology & Oncology Clinic

301 Hawthorne Lane, Suite 100
Charlotte, NC 28204
Phone: (704) 384-1900

UNC Treatment Center

UNC Hemophilia and Thrombosis Center
University of North Carolina at Chapel Hill
Campus Box #7016
Chapel Hill, NC 27599-7016
Phone: (919) 966-4736
htcenter.med.unc.edu

Wake Forest University Baptist Medical Center

The Bowman Gray Campus
Department of Pediatrics
Medical Center Boulevard
Winston-Salem, NC 27157-1081
Phone: (336) 716-4324
Fax: (336) 716-3010

Additional Medical Resources

Carolinas Medical Center Pediatric Hematology/Oncology

1000 Blythe Boulevard
Charlotte, NC 28203
Phone: (704) 381-6800

Duke University Medical Center Hemostasis and Thrombosis Center

DUMC Box 3422
Durham, NC 27710
Phone: (919) 684-5350
htc.medicine.duke.edu

Resource Information

National Hemophilia Foundation
www.hemophilia.org

Hemophilia Foundation of America
www.hemophiliafed.org

**American Society of Pediatric
Hematology/Oncology**
847-275-4716
www.aspho.org

Centers for Disease Control & Prevention
1-800-311-3435
www.cdc.gov

Coalition for Hemophilia B
1-212-520-8272
www.coalitionforhemophiliab.org

ClinicalTrials.gov

A registry of federally and privately supported clinical trials conducted and service of the US National Institutes of Health. It gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health professionals.

Committee of Ten Thousand (COTT)
1-800-488-2688
www.cott1.org

Inalex Communications
201-493-1399
www.inalex.com

LA Kelley Communications
1-978-352-7657
www.kelleycom.com

Patient Notification System

The Patient Notification System is a free, confidential, 24 hour communication system providing information on plasma-derived and recombinant analog therapy withdrawals and recalls.
1-888-UPDATE-U
www.patientnotificationsystem.org

Patient Services Incorporated (PSI)

Assists persons with chronic medical illnesses in accessing health insurance and pharmacy co-payment assistance.
1-800-366-7741
www.uneedpsi.org

World Federation of Hemophilia
1-800-520-6154
www.wfh.org

VISION STATEMENT

Hemophilia of North Carolina's vision is for all persons affected by bleeding disorders to achieve their full potential without barriers or limitations.

Hemophilia of North Carolina is a chapter of the National Hemophilia Foundation, a member organization of the Hemophilia Federation of America, a member agency of Community Health Charities, a member of the NC Center for Nonprofits.



HNC Staff Participates in NHF Regional Leadership Seminar and Visit to National AIDS Memorial Grove

April 9-12, 2018
San Francisco, CA

Each year, the National Hemophilia Foundation (NHF) sponsors two staff members from each affiliated chapter to attend a leadership seminar. This year, more than 100 chapter representatives from around the country gathered in San Francisco, California, to learn from NHF speakers, guest speakers, and one another.

While Gillian (Program Manager) stayed in North Carolina to focus on the Charlotte Family Festival & 5K Walk for Bleeding Disorders, Charlene (Executive Director) and Karyn (Manager of Operations) headed to San Francisco focused on bringing back new ideas to better serve those affected by bleeding disorders here in North Carolina.

The training was very informative with topics that included how to use social media more effectively, donor engagement, educational programming, supporting the diverse needs of the community, how local staff can utilize NHF resources, research, and the coming reduction in financial support from pharmaceutical and specialty pharmacy companies to local chapters' programming and fundraising efforts. With so many changes afoot, it was a valuable experience to gather with other chapter leaders and brainstorm about how to move forward and explore new opportunities for support.

In the midst of all the business of learning and gathering of new ideas, there were also moments of heart-felt inspiration as the attendees heard from Jeanne White-Ginder, mother of Ryan White, and John Cunningham, Executive Director of the National AIDS Memorial Grove. Their presentations about the developing partnership between the HIV and Hemophilia communities to tell the story of those with hemophilia who were infected with the HIV virus were moving. During the AIDS epidemic, over 50% of those with hemophilia in the United States died from the disease as a result of the contaminated blood supply. It was an emotional and inspirational afternoon as representatives of the bleeding disorders community from around the country gathered at the new Hemophilia Memorial to pay tribute to those who lost their lives to HIV/AIDS, as well as the courageous efforts of the hemophilia community who worked to ensure a safe blood supply for all.



Chapter leaders from across the country gather at the AIDS Memorial Grove

Volunteer Opportunities at HNC

There are many ways to support HNC and give back to the community. One way is through volunteering.

With an entire state to cover and a variety of events throughout the year, HNC is finding it necessary to rely on volunteers more and more to ensure the quality and number of events and programs currently available for members throughout the year. This is your chance to make a difference by sharing your time and talents with the members of HNC. Of course, everyone is very busy so if you have limited time or resources to commit, HNC will work with you to find the best volunteer opportunity to fit your needs.

Members from all over the state are welcome to help either in the planning stages or during a program or event itself. Many tasks can be done remotely from the comfort of your own home! Members who are close to the office in Morrisville, NC, can schedule time with HNC staff to help with routine office work and other special projects. Whether you have one day a week or one day a year to dedicate to volunteering, HNC can use your help.

Here are some of HNC's ongoing volunteer needs.

From the comfort of your own home: Post about HNC fundraisers on local event sites to promote events to the general public. Be part of a committee, most meetings are via conference call. Request

donations from businesses in support of HNC programs and events. Proofread the quarterly newsletter.

At the HNC office: Help prepare program materials. Write thank-you notes to HNC supporters. Keep inventory of HNC's education library. Load and unload materials for events and programs.

Translation Services: Are you bilingual? HNC routinely needs assistance with interpreting and translation, especially for our Spanish-speaking members. Whether it's translating documents for the HNC website or interpreting to assist a member, your help is needed.

Special Events Throughout the State:

Find out what special events and programs are happening in your region of the state and sign-up as a volunteer! Duties will vary based on the nature of the event.

If you are interested in being included in the HNC volunteer database, please contact the HNC office.



HNC members can volunteer at events, at the office, or from the comfort of their own home. Contact HNC to find out more!

The Men's Retreat, for All Men in the Community

July 20-22, 2018
Blowing Rock, NC



Men of the community gathered at the 2017 Men's Retreat

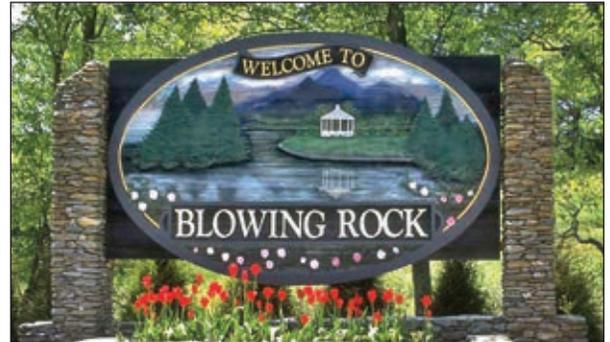
Are you an adult male, 18 or older, living with a bleeding disorder, a dad of someone with a bleeding disorder, OR a husband/partner of someone with a bleeding disorder? The HNC Men's Retreat is an event designed to support all men in the community through mentoring, common connections, and friendship.

The location for this year's retreat is the Blowing Rock Conference & Retreat Center in the North Carolina mountains, just off the Blue Ridge Parkway. In addition to the beautiful scenery, the conference center features meeting rooms that are wheelchair accessible with most guest rooms being on the first floor. All meals and accommodations will be provided and gas cards to assist with travel expenses will be available if requested.

This year's program will include a mixture of programs provided in part through the

Hemophilia Federation of America (HFA) on Friday evening and Saturday along with plenty of time to relax, explore, and enjoy the surrounding area. The event will conclude with an optional, relaxing tubing trip down the river.

Registration is required by July 10. Registration is open now online (preferred) www.hemophilia-nc.org, or by calling the HNC Office toll free at (800) 990-5557.



Men's Retreat heading to Blowing Rock, NC. Register today

Latin Union Retreat

July 28-29, 2018
Winston-Salem, NC

Please join HNC for the first ever Latin Union Retreat on July 28-29 at the Hawthorne Inn & Conference Center in Winston-Salem, for a weekend of education, camaraderie, and fun. This retreat weekend will feature programming entirely in Spanish. There will be a mixture of educational and fun programs for all ages. Accommodations will be provided on Saturday night along with lunch and dinner on Saturday, and breakfast and lunch on Sunday. There will be travel assistance, including a chartered bus leaving Greenville, NC, at 5:45am on Saturday morning with a stop at the HNC Office in Morrisville, NC, before heading to Winston-Salem for a 10:00am arrival. Gas cards will also be

available to members who plan to drive to the event. If travel assistance is needed that is not listed, please contact the HNC office so arrangements can be made.

We encourage all HNC members who are native Spanish speakers to attend this event. It will provide an opportunity to get to know other Spanish-speaking HNC members in a supportive environment. Registration is required by July 3. Please register on the HNC website or email Gillian Schultz, HNC Program Manager at events@hemophilia-nc.org, or text her at (919) 272-6000.

Join the Fun in the Sun at the HNC Family Day Out

August 19, 2018
Clemmons, NC

Please join fellow HNC members for the third annual Family Day Out at Tanglewood Park in Clemmons, NC! Come out for this fun, one-day social gathering with others in the bleeding disorders community. Find out more about HNC, meet and mingle with other families from across the state, and enjoy activities and games, lunch, and an opportunity to visit the Aquatic Center. In addition to swimming pools, the Aquatic Center includes a winding tubing river, waterslides, a splash pad and kiddie pool with fun water features, a lap pool, and more.



Members enjoy a picnic lunch before heading to the water park at the 2017 HNC Family Day Out

Registration is required by August 8. When you register, please be sure to note if you will be enjoying the Aquatic Center or just coming for lunch and activities. Registration is open now online (preferred) www.hemophilia-nc.org, or by calling the HNC Office toll free at (800) 990-5557.



The Tanglewood Park water park is a fun way to end a hot summer day

70th NHF Bleeding Disorders Conference

October 11-13, 2018
Orlando, FL



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

The beautiful Orlando World Center Marriott. This conference is three days full of educational sessions, networking opportunities, and exhibit hall access. Registrations include entrance to the

The National Hemophilia Foundation's (NHF) 70th Bleeding Disorders Conference will be held October 11-13, 2018 in Orlando, Florida, at

Opening Session, Awards Luncheon, and the exciting Final Night event. Childcare is available for children under 12 years old. Visit www.hemophilia.org to register and for more information about the event.

While it is a considerable commitment of time and money, HNC would encourage all members to make the effort to be part of this event. For more information about travel grants and registration, please contact the HNC office.

Family Retreat Moves to the Great Wolf Lodge

October 19-21, 2018
Concord, NC



The Family Retreat is fun for kids

The ever-popular HNC Family Retreat will be taking place at the Great Wolf Lodge in Concord from October 19-21. This event has proven to be extremely valuable with helping both parents and kids navigate the world of having a bleeding disorder.

Families who have a child or children with a bleeding disorder, ages 12 and under, are invited and childcare will be provided. This event is a perfect opportunity to spend time with other families for a weekend filled with educational programming and offers plenty of free time to be able to focus on building relationships with other families. All families, whether connected already or new to the community can benefit from the ability to bond with fellow community members.

Be on the lookout for more announcements about this year's Family Retreat as the date approaches. Registration will be required. Priority registration will be given to families having a child age 12 or under who is diagnosed with a bleeding disorder.



And it's fun for adults too

They Shoot, They Score! HOPE Educational Event and Hockey Game

March 17, 2018
Charlotte, NC

March 17 was a lucky day for the Charlotte Checkers and HNC members got to watch the excitement. The afternoon started with an educational program to share the importance of staying active with a bleeding disorder. Lee Houston and Jecorei Lyons from Drugco Health talked about the importance of physical fitness. Jecorei shared his story of telling his Hemophilia Treatment Center that he wanted to be a breakdancer and the steps that he had to take in order to successfully participate in hip-hop dancing. Many HNC members are familiar with Jecoreigraphy, the dance group that Jecorei started. Their performance is now a tradition at each HNC Family Festival & Walk.



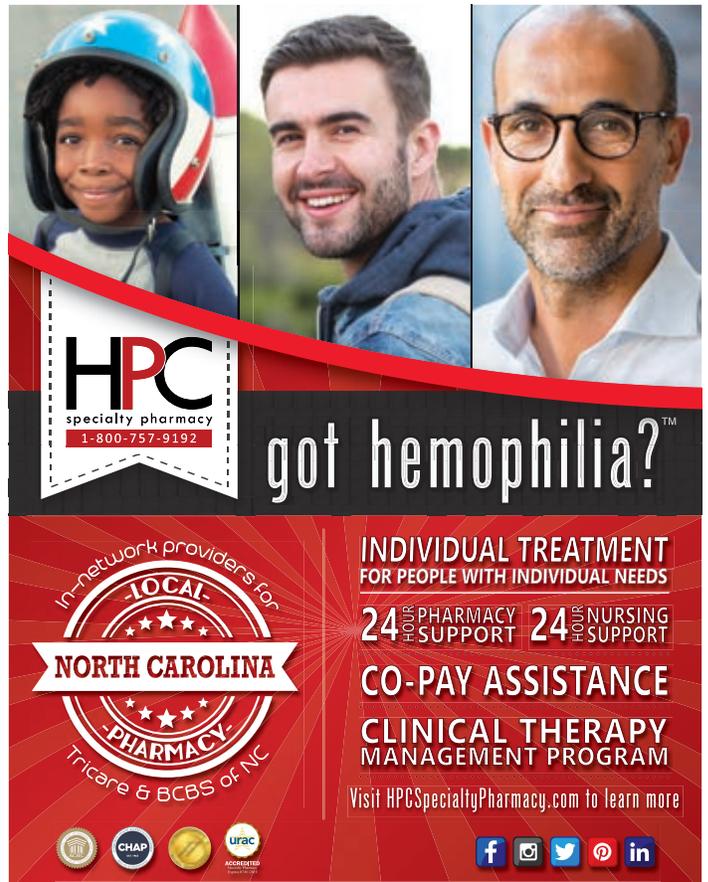
HNC members learn about the importance of physical fitness

Following the education portion of the event, attendees walked over to the “on-ice suite” where a buffet dinner was waiting for them, along with chairs and tables along the boards. The game was action packed and HNC members were able to feel like they were part of the action being so close to the ice. After an exciting 3 periods, the Charlotte Checkers won 4-2!



This program was part of HNC’s HOPE Program, for families with children with bleeding disorders. Thank you to Drugco Health for partnering with HNC to make this event possible!

Left: Members enjoy dining along the boards



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Right: Chubby, the Charlotte Checkers’ mascot, having fun with HNC members

HNC Family Festival in Charlotte Keeps Growing

April 14, 2018
Charlotte, NC

Mint Street in Charlotte came alive before dawn the day of the 4th Annual Charlotte Family Festival & 5K Walk for Bleeding Disorders as volunteers arrived to unload, set-up, and get ready for the walkers to arrive for the festivities. It takes the entire community of dedicated members, volunteers, sponsors, donors, and contributors to give their time and effort to make this event a success, and that's exactly what they did to help HNC reach beyond it's goal by raising \$69,810!

The event took place on Mint Street between the Charlotte Knight's BB&T Ballpark and Romare Bearden Park with more than 400 in attendance. HNC members and supporters spread awareness through the streets of Uptown Charlotte as they gathered in the event area and walked through the neighborhood attracting members of the local community to stop by to learn more about HNC and the community it serves.

Sponsored activities were also on the list of fun things to do while walkers were arriving before the walk's official start. With the balloon artist sponsored by Drugco Health and photobooth sponsored by Aptevo Therapeutics, as well as carnival games, sand art, face painting, and spin art, there were plenty of options for all. Those at the Festival also had a chance to enjoy the basketball

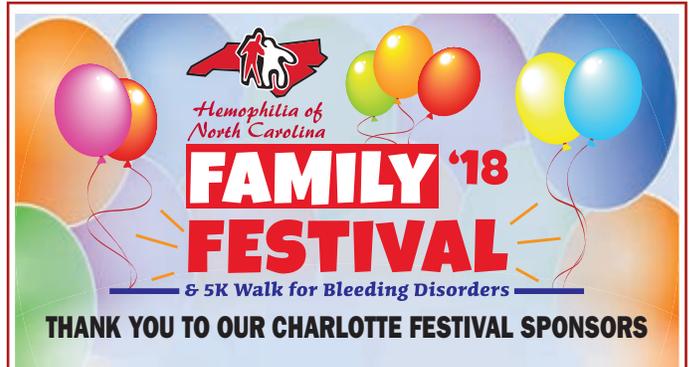
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Volunteers hard at work checking in walkers



Freddy's Frozen Custard was an easy way to cool down after the Walk



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HNC Family Festival in Charlotte Keeps Growing *continued from previous page*



2018 HNC Charlotte Festival King, Queen, and Jr. Droplets



2018 HNC Charlotte Festival top fundraiser, Will Hodges

shoot-out activity area where kids had a chance to win in a drawing for some great prizes.

It was a sunny day with plenty of activities and great food to eat. In-kind donors generously provided food for members to enjoy throughout the day. With coffee donated by Starbucks, Bagels provided by Einstein Brothers Bagels and the Schultz Family, and juice and granola bars from the Holland and Stephenson Families, everyone had a chance to grab a bite to eat before getting started on their walk. Once the walk was complete, participants returned to lunch provided by Will's Dogg'n It Deli and Mellow Mushroom Pizza along with free sundaes from Freddy's Frozen Custard & Steakburgers in Concord. To keep folks hydrated throughout the day, Pepsi once again provided bottled water. Finally, the dogs were treated too with doggie-treats donated by Canine Café.

Carolyn Bruck, morning anchor, WCNC, got the festivities started while Jecoreigraphy and Performance DJ kept the crowd moving. HNC once again awarded the King, Queen, and Jr. Droplet awards to three people in the community who made a great effort to support the event and made special contributions to the Festival this year. Congratulations to this year's Droplet winners Karl Schultz, Linda Hodges, and Diego and Felix Mayle, and thank you to Joyfully Sewn Endeavors for making the winners' sashes.

For the second year in a row, St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital won the coveted Charlotte Hospital Cup, but what made it extraordinary was that they were also the Top Team for this year's Festival by raising \$6,706 in team donations. Rounding out the top three teams were Will Power, raising an amazing \$5,731, and Team G-Man with a total of \$2,670. In fact, with funds included from the next two teams in line, South Cows and Hulk Smash, the top five teams at this year's Charlotte Family Festival & 5K Walk for Bleeding Disorders raised a total of \$19,416! Congratulations to all members of these dedicated teams.



Face painting was one of the many fun activities at the 2018 HNC Charlotte Festival



People and dogs of all ages had a lot of fun at the 2018 HNC Charlotte Festival

With the Walk complete and lunch served, it was time for the raffle prize drawing. One lucky adult went home with Bose SoundLink wireless headphones, while others won drawings for Charlotte Knights Baseball Tickets, a gift card from Firebird's Wood Fired Grill, or passes to the Carolina Raptor Center. Kids also had a chance to win raffle prizes. Three lucky kids took home either an autographed Charlotte Hornets Basketball that was signed by Marvin Williams, a certificate for a birthday party at Charlotte Allstars Gymnastics & Cheerleading, or Dave & Busters Power Cards. Then, new this year, a raffle drawing for those who stopped by the tent of the Festival's Presenting Sponsor, Grifols, to find out the answer to a special trivia question. For a chance

Continued next page

To see pictures and video clips of the event, please visit our Facebook page <https://www.facebook.com/HemophiliaNC>. More photos and videos will be added as they continue to roll in. If you aren't already a page member, simply "like" us and continue to see HNC news, events, and pictures throughout the year.

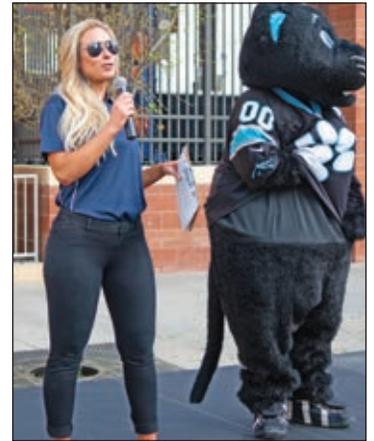
HNC Family Festival in Charlotte Keeps Growing *continued from previous page*



2018 HNC Charlotte Festival Hospital Cup Winners, St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital Team

to win a \$25 BP gas card, participants had to have the correct answer to the question, "HNC opened its first office in the early 1980s –where?" The answer: Chapel Hill.

HNC would like to extend a special thanks to everyone who played a part in making this event a success. Without the support of every member, sponsor, volunteer, donor, and contributor, none of this would have been possible. It is inspiring to see this event growing each year, which allows HNC to continue meeting the mission of supporting the NC bleeding disorders community.



Event emcee, Carolyn Bruck, morning anchor, WCNC

SAVE THE DATE: Join us for the 11th Annual HNC Family Festival & 5K Walk for Bleeding Disorders at Lake Crabtree Park in Morrisville on September 15, 2018, and the 5th Annual HNC Family Festival & 5K Walk for Bleeding Disorders in Uptown Charlotte on April 27, 2019!

The hemophilia treatments of today were once the dreams of yesterday. Proof that when

SCIENCE AND THE COMMUNITY

come together, great things happen.

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Let's put science to work

GenentechHemophilia.com

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Actualización del Programa Unión Latina

El Programa Unión Latina del HNC continua con su labor de proveer recursos y apoyo para los miembros de habla Hispana de la comunidad de HNC. El 3 de Junio, los miembros se reunieron para visitar el Zoológico de NC, en Asheboro para disfrutar de un picnic, una presentación y una visita al zoológico. Otros eventos que vale la pena destacar y que se realizarán durante el presente año serán, el 11 de Agosto en Raleigh; el 1 de Diciembre en Concord; y el primer Retiro de la Unión Latinoamericana, que se

efectuara el 28 y 29 en Winston-Salem, NC.

La Unión Latina es un programa del HNC designado para ayudar y educar a individuos de origen Latino y sus familias, en North Carolina y que sufren de enfermedades hemorrágicas. El programa, ofrecido en Español, es posible gracias al auspicio de Shire. Para mayor información, visite el sitio web de HNC.

Evento de la Unión Latina

24 de Marzo del 2018
Concord, NC

Aunque en el exterior había un día gris y aburrido, para varias familias de la Unión Latina fue el día perfecto para reunirse, conectarse y educarse en Dave & Buster's, en Concord. Una vez que todos los asistentes arribaron pudieron aproximarse al buffet y probar la selección de los BBQs, provenientes de distintos puntos del país. Luego del almuerzo, los participantes se instalaron a escuchar charlas de Hello Talk! acerca de como las hemorragias afectan al organismo. A través de Como Reconocer y Atender una Hemorragia, presentada por Yinel Núñez, Educadora Bilingüe de Salud de Shire, la audiencia aprendió cuan rápido una hemorragia puede dañar articulaciones, y también formas de mantenerse en buen estado de salud.

Continuando con el programa, las familias fueron agasajadas con una tarde recreativa, jugando en Dave & Buster's. Gracias a Shire por el auspicio ofrecido al Programa Unión Latina de HNC, el cual permite a los miembros de habla Hispana a educarse acerca de sus enfermedades hemorrágicas, en Español.



Retiro de la Unión Latina

28 y 29 de Julio del 2018
Winston-Salem, NC

HNC tiene el placer de invitarles al primer Retiro de la Unión Latina, el 28 y 29 de Julio, en el Hawthorne Inn & Conference Center en Winston-Salem, para participar de un fin de semana donde se ofrecerá educación, camaradería y diversión. Este Retiro será ofrecido enteramente en Español y será una combinación de actividades educativas y de entretenimiento para todas las edades. Las reservas hoteleras incluyen el alojamiento para el Sábado, almuerzo y cena, y también desayuno y almuerzo para el Domingo. El programa también ofrece asistencia de viaje, que incluye viaje en bus, saliendo de Greenville, NC el Sábado a las 5:45 AM con una parada en la oficina de HNC en Morrisville, antes de dirigirse a Winston-Salem, llegando allí a las 10:00 AM. Tarjetas para gasolina gratis estarán disponibles para los miembros que planeen manejar hasta el evento. Para asistencia de viaje, no mencionada en este artículo, por favor contactar la oficina de HNC para conseguir las acomodaciones necesarias.

Invitamos cordialmente a los miembros del HNC de habla Hispana a asistir a este evento. El Retiro ofrecerá la oportunidad de conocer a otros miembros latinos de esta comunidad, enmarcado en un ambiente de ayuda y amistad.

La asistencia al Retiro requiere inscripción, antes del 3 de Julio. Por favor regístrese en el sitio web del HNC, o contacte por email a Gillian Schultz, Gerente del Programa del HNC, events@hemophilia-nc.org, o envíele un mensaje de texto al (919) 272-6000.

La Unión Latina visita el Zoológico

3 de Junio del 2018
Asheboro, NC

Fue un día cálido para el evento de la Unión Latina en el Zoológico de Carolina del Norte, en Asheboro, NC. La tarde comenzó mientras las familias se actualizaban entre ellas y disfrutaban de un rico buffet de barbeque. Patricia Espinosa-Thomson, Educadora Bilingüe para Pacientes, de Shire, presento *Hello Talk!*

El Camino para Manejar de su Salud Independientemente donde las familias discutieron como hacen para fomentar la independencia con sus hijos. Ya sea que su hijo tenga 3 o bien 16 años de edad, distintas estrategias pueden ser implementadas, durante las distintas etapas de su desarrollo. Recibir infusiones, aprender a administrarse sus propias infusiones, la importancia de ordenar suministros, y hasta compartir la toma de decisiones con su doctor, fueron algunos de los temas expuestos. Luego de la presentación, las familias tuvieron la oportunidad de disfrutar las exhibiciones y los diversos animales del zoológico. Gracias Shire por el apoyo a la Unión Latina.



Miembros de la Unión Latina disfruta el Hello Talk! antes de su visita al zoológico



SOAR Program Update

The SOAR Program has been gaining momentum over the past few months. Final details were put in place for the SOAR Retreat, which took place on June 23-24 in Greensboro, just as this edition of *The Concentrate* was being prepared to be mailed. There were sessions for both women and teenage girls with bleeding disorders. More details of the event will be available in the Fall edition of the newsletter. The momentum goes on as HNC is continuing to grow the Women's Advocacy Coalition (WAC) to help advocate and raise awareness for women and girls with bleeding disorders. Finally, as the year continues, there will be more educational opportunities before the close of 2018.

SOAR is an HNC program for women and girls with a bleeding disorder, including those diagnosed with von Willebrand disease, hemophilia A and B, rare factor deficiencies, platelet disorders, and carriers of any of these disorders (both symptomatic and non-symptomatic). The mission is to improve the quality of life for girls and women with bleeding disorders, so that they my SOAR to their full potential.

Please contact Gillian Schultz, HNC Program Manager, for more information about the SOAR Program at soar@hemophilia-nc.org or by calling the HNC Office at (800) 990-5557.

Missing work or school because of heavy periods?



If so, ask your doctor about the possibility of a bleeding disorder.

Other symptoms may include:

- Easy bruising
- Frequent or prolonged nosebleeds
- Prolonged bleeding after injury, surgery, childbirth, or dental work

On average it can take a woman with a bleeding disorder **16 years** to get an accurate diagnosis. Don't wait. Get help now.



SOAR is a Hemophilia of North Carolina program for girls and women with bleeding disorders. Please contact us for more information on women's bleeding disorders.



1-800-990-5557
soar@hemophilia-nc.org
www.hemophilia-nc.org/soar.html



Get involved!

Post these flyers inside the bathroom stalls where you work or go to school to help spread awareness about women with bleeding disorders.

Need flyers? Contact the HNC office.

Membership Information

For more information about SOAR, or to be added to the SOAR mailing list, please send your name and contact information, along with any questions you may have, to soar@hemophilia-nc.org.

Support • Outreach • Advocacy • Resources
SOAR's Mission Statement: To improve the quality of life for girls and women with bleeding disorders, so that they may SOAR to their full potential.

An HNC Program for Girls and Women with Bleeding Disorders

Women’s Advocacy Coalition

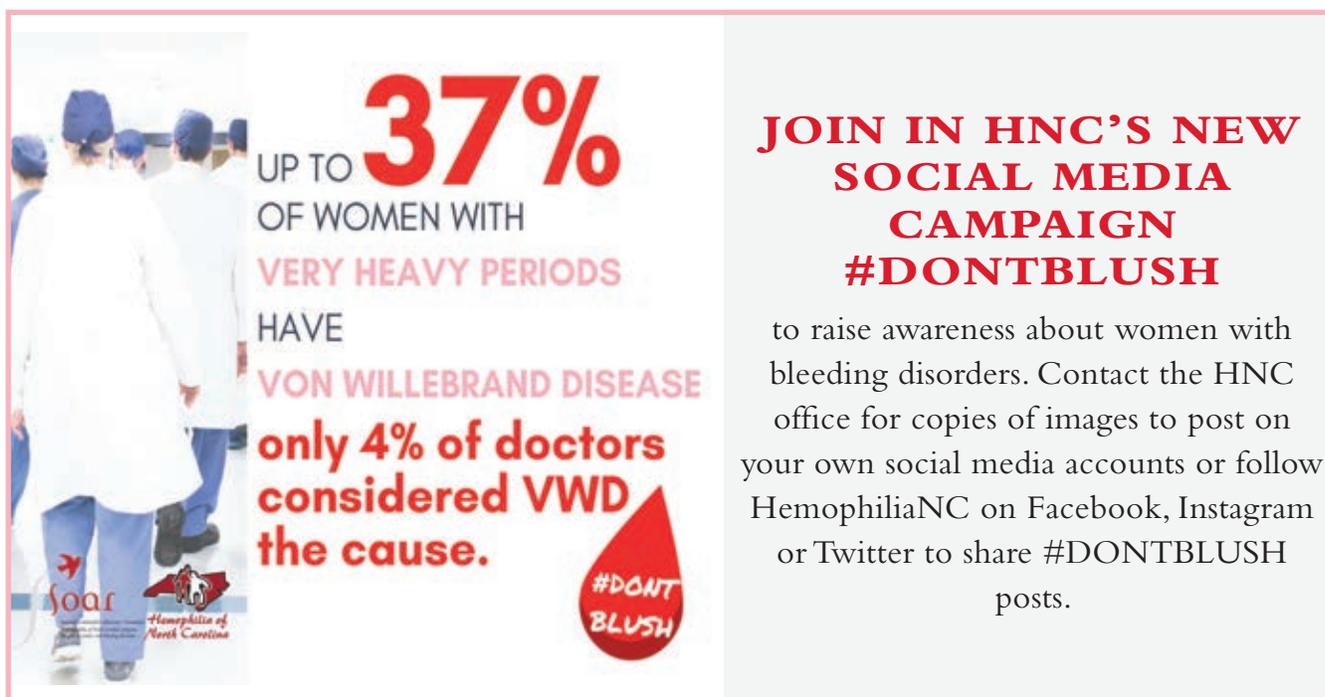
SOAR stands for *Support, Outreach, Advocacy, and Resources*. Since the inception of the SOAR Program, HNC has been providing these services at varying degrees over the years. The Women’s Advocacy Coalition was developed to further expand upon the outreach and advocacy efforts that women of SOAR have the enthusiasm for and to help all women and girls affected by bleeding disorders.

The vision of the Women’s Advocacy Coalition is to raise awareness for women and girls with bleeding disorders and to advocate for a quicker diagnosis and appropriate treatment. While still in its infancy, the committee has been meeting regularly to determine the best way to meet this vision. They have developed two main arms for the initiative, an outreach arm and an advocacy arm, which in turn will work hand-in-hand.

The outreach arm of the Coalition is working to develop a social media campaign. You may have seen the #DontBlush Campaign on Facebook, Instagram, and Twitter. This social media campaign will be working to raise awareness not only in the bleeding disorders community, but to women and girls not diagnosed with a bleeding disorder. By posting information and statistics about women with bleeding disorders, the committee hopes to raise awareness about the signs and symptoms of a bleeding disorder in women. As you see these posts on social media, please help by sharing them. It takes help from everyone in the community to help this initiative grow to what it can be!

The advocacy arm will continue HNC’s role of exhibiting at nurse’s conferences across North Carolina. In addition, they will be looking to expand their advocacy through legislative advocacy and reaching out to other groups and organizations that likely come in contact with women and girls who have symptoms of bleeding disorders, but are not yet diagnosed. By expanding the reach to OBGYNs, dentists, colleges, and other organizations, HNC can raise awareness and help to advocate for quicker and better treatment.

For more information about the Women’s Advocacy Coalition, please contact Gillian Schultz, HNC Program Manager, at soar@hemophilia-nc.org or by calling the HNC Office at (800) 990-5557.



UP TO 37%
OF WOMEN WITH
VERY HEAVY PERIODS
HAVE
VON WILLEBRAND DISEASE
only 4% of doctors
considered VWD
the cause.

#DONT BLUSH

**JOIN IN HNC’S NEW
SOCIAL MEDIA
CAMPAIGN
#DONTBLUSH**

to raise awareness about women with bleeding disorders. Contact the HNC office for copies of images to post on your own social media accounts or follow HemophiliaNC on Facebook, Instagram or Twitter to share #DONTBLUSH posts.

Young Members Supporting HNC

Have you ever wondered how you can support HNC? Did you think you were too young to make a difference? This year's Charlotte Family Festival Jr. Droplet winners, Diego and Felix, found creative ways to fundraise and increase awareness about bleeding disorders, especially von Willebrand disease (VWD). If you're out there making a difference like Diego and Felix, send HNC your story to highlight in a future edition of *The Concentrate*.

By: Felix, age 12, HNC Member

This year my family and I decided to have a bake sale to raise money for the HNC walk. Three years ago we formed Team Diego, in support of my brother, who has von Willebrand disease. I think the reason why we wanted to fundraise for the walk was to give back for all the support HNC has given us over the years. HNC is very important to my family. When my brother was diagnosed they helped us learn about his disease. My brother and I have made friends through the years of attending meetings and events. My mom says she has learned a lot through meetings and she is very grateful she was told about HNC when Diego was diagnosed. My brother would like to open a bakery one day. We spend many weekends baking and decorating cookies. We have cookie decorating parties at our house with friends. My memaw would always take cookies into her work and her co-workers loved them. We got the idea to make some ribbon cookies and sell them and give all the money to HNC. My memaw's co-workers bought them all and started to ask her to bring more. So we made more sweets. We made pound cakes, fudge, and no bake cookies.

I told a teacher at my school about our fundraiser and she volunteered to help sell our baked goods at my school. Several teachers were excited to buy the items when they heard what it was for. My homeroom teacher donated money to our team. In a few weeks we had made over \$300. We have set a goal for next year's walk. We will start the bake sale sooner this year so we can meet our goal.



Bake Sale to raise funds and awareness about VWD and bleeding disorders

By: Diego, age 15, HNC Member

My name is Diego. I am 15 years old and I have von Willebrand Type-IIA. I was diagnosed at age 2 ½ but didn't start prophylaxis until I was 5. I wanted to play baseball so my hematologist said I had to get regular infusions before practice and games. When I was 6, I started questioning how my medicine was made. My mom explained that it came from blood. My birthday was coming up and I told my mom I wanted to thank the people who kept me alive instead of having a birthday party. My family talked about different things we could do and came up with the idea to host a blood drive. I told my family I wanted to do this each year so that we could help make sure there was always blood for my life saving medication. (At age 7 I had no idea the amount of blood donors needed to make my medication.)

In June 2008 we hosted the first blood drive. We had 40 plus people give at my first drive, 30 plus of those people were first time donors. I was overwhelmed with the number of people who showed up to support me. I greeted each donor and told them thank you. Diego's Annual Blood Drive became a yearly drive.

Over the years, we have continued to host a blood drive around my birthday in May. We have hosted 10 blood drives since 2010. Many of those first time donors have become regular donors. I have done interviews for the newspaper and TV to promote blood drives. I have had a few different businesses host blood drives in my honor.

I still believe it is important for my family and I to host blood drives. I recently had an accident playing basketball. I sprained my ankle pretty bad and had to be in a cast for 3 weeks and now a walking boot. In the past 7 weeks, I have had 63 infusions for this injury. If there were not people out there promoting and hosting blood drives, I never would have had the medicine I needed for this injury.

I am very grateful that a lot of people are not scared of needles and are willing to donate their blood. I am sure you hear stories like mine every day. I appreciate you taking the time to read my story. I hope my story has inspired you to donate blood or host a blood drive. Please pass my story on to inspire others to donate.



Diego and Felix at their first annual blood drive

Educational Dinners Around the State

HNC encourages members to attend educational dinners in their area as a way to learn more about living with and navigating through life with a bleeding disorder and to meet others in the community. If there is a topic of interest you wish to be brought to your area of the state, please contact the HNC office.

Learning About Inhibitors

March 22, 2018
Fayetteville, NC

A group of HNC members joined together in Fayetteville at Luigi's Restaurant and Bar to learn about inhibitors. After spending some time catching up, Sue Geraghty, RN, provided information about what an inhibitor is, who gets inhibitors, how to treat them, and ways to live healthy with an inhibitor. Guests shared their experiences living with inhibitors and asked a variety of questions. One important fact from the evening was how important it is for all people living with hemophilia to get tested for inhibitors once a year. Even those living with mild hemophilia can be affected, which some people do not realize. Following the presentation, a delicious dinner, and lively conversation, everyone said their farewells until the next event. Thank you to Novo Nordisk for making this educational opportunity possible.



HNC Members learn about inhibitors in Fayetteville, NC

Recognizing and Responding to a Bleed

March 24, 2018
Concord, NC

It was a dreary afternoon outside making it a perfect day for several Latin Union member families to come together for the opportunity to connect and learn at Dave & Buster's in Concord. Once everyone arrived, attendees visited the buffet for a selection of BBQ from around the country. Then, they settled in to learn about how bleeds affect the body during the Hello Talk! *Recognizing and Responding to a Bleed* presented by Yinell Nunez, Shire Bilingual Healthcare Educator. Those in attendance learned how quickly a bleed causes damage to a joint and ways to stay healthy. Following the program, families were treated to an afternoon to enjoy the arcade at Dave & Buster's. Thanks to Shire for sponsoring the HNC Latin Union Program which allows the Spanish speaking members of HNC to learn about their bleeding disorder in Spanish.

HOPE Infusion Support

May 16, 2018
Durham, NC

HNC members came out to Durham for a night of community support and education as they gathered at Maggiano's Little Italy for the Pfizer program entitled, *Infusion Support for Caregivers of Patients with Hemophilia*. Linda Pollhammer, BSN, RN, a Patient Affairs Liaison for Pfizer Hemophilia, provided an overview on infusion techniques and best practices while attendees enjoyed a wonderful dinner. Even though the program was geared toward HNC's HOPE Program participants for families with children ages 12 and under who have a bleeding disorder, all members of the community left with new information and a better understanding of infusion and adherence to treatment regardless of what kind of care and management a person's bleeding disorder requires. Thanks to Pfizer Hemophilia for sponsoring this educational program for HNC members.

Managing Healthcare Independently

June 7, 2018
Asheville, NC

HNC headed west to support families who live in western North Carolina. It was a beautiful early summer evening as families gathered at The Cantina in the Historic Biltmore Village in Asheville for an educational dinner and presentation. After everyone got their food, Besty Koval, Senior Clinical Specialist with Shire, presented the Hello Talk! *Managing Healthcare Independently*. She detailed the different stages of "letting go," including allowing others to watch your children, sending your children off to school, self-infusion, puberty, and growing into adulthood. Families shared some of their own experiences with helping their children to gain independence along with some challenges that they have had to deal with. After sharing some tools to help parents and children learn about being more self-sufficient, and some delicious dessert, everyone left with some new connections and resources to help them. Thank you to Shire for sponsoring this educational program.



HNC members gather in Asheville

HNC is thankful for the corporate partnerships that help make these educational dinners possible.

World Hemophilia Day Celebration Lights Up Red in Charlotte

April 17, 2018
Charlotte, NC

Members of Hemophilia of North Carolina (HNC) and Hemophilia of South Carolina (HSC) came together for a special joint celebration of the 28th Annual World Hemophilia Day in Charlotte, NC. The evening began with a buffet dinner at the Embassy Suites, followed by the Bioverativ presentation “Science Matters!” a highly interactive science activity to show how scientists test for a factor deficiency in the clotting cascade.



HNC and HSC Members participate in the “Science Matters!” activity



*Duke Energy Center
in Uptown Charlotte
Lights it Red*

After dinner and all science experiments were finished, attendees headed outside for a special treat.

As in past years, the Wells Fargo Duke Energy Center in Uptown Charlotte was selected as one of the many landmarks around the world for the World Federation of Hemophilia’s (WFH) *Light it Red* effort to honor and show support for all people with bleeding disorders around the world.

It was a special evening, having members from HNC and HSC together for such a meaningful occasion. This event is a reminder for members of the bleeding disorders community, as well as members of the general public, about the state of bleeding disorders around the world. It is not known exactly how many people around the world have a bleeding disorder, but it is estimated that 75% of those people do not have access to adequate treatment and care. This year, the WFH is focusing its efforts on sharing knowledge. The bleeding disorders community is filled with first-hand knowledge, experience, and wisdom needed to increase awareness and improve access to care and treatment.



*Members of HNC and HSC join together to
celebrate World Hemophilia Day*

HFA Symposium

April 26-29, 2018
Cleveland, OH

The Hemophilia Federation of America (HFA) hosts an annual Symposium each year in a different part of the country. This year, attendees found themselves in Cleveland. What’s in Cleveland, you ask? Lots of things, but most notably is the Rock & Roll Hall of Fame. The Symposium’s theme, *Together We Rock*, tied in perfectly.

More than 1,050 attendees from around the world made their way to Cleveland for this important event. Hemophilia of NC was well represented with 15 people in the crowd and nobody went home disappointed. The Symposium offers community members the opportunity to learn and grow. During powerful sessions, community members were able to meet and bond on a personal level with other community members and presenters. Some topics included updates on ongoing research, opioid prevention and dependency, parenting stress and social support, care of rare bleeding disorders, pain management: comprehensive care and medical marijuana, aging in women with bleeding disorders, and much more. One very special session, the Remembrance Service, is held annually at the Symposium and something that everyone should attend. It is a time to honor those that came before us and share the names of people that have left an everlasting impression on the community, making the brighter future ahead possible through fighting battles that some of us will never have to face because of them.

After all of the sessions were over, it was time to ROCK! Everyone headed over to the Rock & Roll Hall of Fame for an evening of exploration, dinner, drinks, and dancing. You could feel the energy in the building as people celebrated the fantastic symposium.

Unión Latina at the Zoo

June 3, 2018
Asheboro, NC



It was a warm day for the Latin Union event at the North Carolina Zoo in Asheboro, NC. The afternoon started with families catching up with each other and getting some food from the delicious barbeque buffet. Patricia Espinosa-Thomas, Shire Bilingual Patient Educator, presented a Hello Talk! *Road to Managing Your Healthcare Independently*, where families discussed what they do to foster independence with their children. Whether your child is 3 years old or 16 years old, different strategies can be implemented through the different stages of growing up. Sitting for infusions, learning to infuse on your own, ordering factor and supplies, and making your own individual healthcare decisions alongside your doctor, were among the topics discussed. Following the presentation, families were able to experience the exhibits and animals at the zoo. Thank you to Shire for supporting the Latin Union Program.

HNC's Summer Events

There are several exciting summer events taking place throughout June and July that could not be included in this edition of *The Concentrate* due to the newsletter's production schedule. HNC will be bringing updates to members about Summer events and activities in the Fall 2018 edition. These events include: Summer Educational Dinners, HNC Legislative Day, the Blood Brotherhood Retreat, the SOAR Retreat, and the Teen Retreat.

2018 Friends of HNC

We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2018. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.

General Donations

Asif Ansari
Gay A. Boggess
Mark & Jo Anne Buckley
Irene Cowell
Mr. & Mrs. W. Allen Heafner
David Reneau
Nancy Smoak

In Honor of Barbara Hargett

Brandon & Tiffany Hargett

In Honor of Sara Jane Hodges

Melissa Pluchos

In Honor of Will Hodges

Cindy Thomas
Janet & William Turner

In Memory of Christopher Dwayne Oxendine

Tisha Locklear

In Memory of Thomas Gordon

Kenneth & Cynthia Sevier

Pfizer "Pi Day" Fundraiser

Pfizer employees from
Sanford, NC Facility

In Memory of Warren Jewett

Ruth Anderson	Chris Perrins
Holly & Robert Ardinger	Harold & Joan Plassman
James Burke	Phillip Poovey
Daniel Burns	Joseph Rattien
Charles & Susan Cowell	Nathaniel Rohrbaugh
Dianne Cruz	Judith Rupp
Friends at Williamsburg Commons	Ann M. Saunders, PhD & the staff at Zinfandel Pharmaceuticals, Inc.
Lisa Gwyther	Megan Shepherd-Banigan
Annette Hastie	Kelly Tetter
Christopher Hitchcock	Courtney Van Houtven
Kenneth Langa	James & Janet Wyse
Mildred Mitchell	



- Help
- Opportunity
- Partnership
- Empowerment

HOPE Program Update

Hemophilia of North Carolina strives to develop programs that will meet the diverse needs of its members. One such program is the HOPE Program for families with children 12 and under with a bleeding disorder. Over the years, this program has grown to include educational dinners, a session at the Annual Meeting, the popular Family Retreat, and the Mentoring Program to help parents and other caregivers navigate the challenges that raising a child with a bleeding disorder presents. However, not everyone is being reached. Whether it is because of your address, family and work schedule, feeling nervous about attending an event, or any other reason, if you are looking for support and community, HNC wants to provide that to you. With those ideas in mind, new initiatives are being developed to reach the greater community.

The first of those ideas is to start Regional Area Groups. These groups would be led by another parent in different parts of North Carolina, whether in the mountains, the beach, or somewhere in between. Events will be casual and could include playdates, picnics in the park, or other ideas that people come up with. This can help people get to know each other in a more relaxed fashion and allow your kids to grow up together. This program is still in development and several months from becoming a reality. Keep your eyes on Facebook and other social media, your email, and future newsletters for more information.

The second idea is to have a greater online presence. With the prevalence of Facebook, Instagram, and other social media platforms, many people go online for support. There are many Facebook groups that provide support for people with bleeding disorders. HNC already has a HOPE Facebook group, although it is currently inactive. The goal is to use this and other platforms to re-engage the community online as this is how many people find support. As this comes closer to reality, you will be informed by email, social media, and other means.

If you have other ideas of how to strengthen and grow the HOPE Program, please contact the HNC Office.

For more information about the HOPE Program contact Gillian Schultz, HNC Program Manager at gillian.schultz@hemophilia-nc.org, by calling Gillian directly at (919) 272-6000, or by calling the HNC office at (800) 990-5557. You may also check the HNC webpage, Facebook, Twitter, and Instagram pages, and your email for updates about upcoming programs and events.



Blood Brotherhood

Blood Brotherhood Program Update

2018 has been a great year so far for the HNC Blood Brotherhood.

With events having already taken place so far this year in Chapel Hill, Winston-Salem, and Pine Knoll Shores, it's not too late for members to join the Blood Brotherhood at the year's remaining events in Blowing Rock, Lumberton, and Hickory.

Save the date for Blood Brotherhood events currently scheduled to take place in Lumberton on September 29, and in Hickory on December 15. In addition to these one-day gatherings, Blood Brothers can register now for the HNC Men's Retreat on July 20-22 by visiting the HNC website. For more information on the Men's Retreat, please see the article on page 4 in this edition of *The Concentrate*.

HNC's Blood Brotherhood is an extension of HFA's Blood Brotherhood Program. It's designed to provide opportunities for men with bleeding disorders to get together both in person and online to discuss their issues with each other and with caring professionals. If you can't make an event consider connecting with adult men with bleeding disorders from the comfort of your own home with the new and improved Blood Brotherhood private online forum! Go to www.hemophiliafed.org to register.

Latin Union Program Update

The HNC Latin Union Program continues to provide resources and support for Spanish speaking members of the HNC community. On June 3, members got together at the NC Zoo in Asheboro for a picnic lunch, presentation, and visit to the zoo. Other educational events throughout the year will be on August 11 in Raleigh, December 1 in Concord, and at the first ever Latin Union Retreat, taking place July 28-29 in Winston-Salem, NC.

The Latin Union is an HNC Program designed to support and educate Latino individuals and families in North Carolina who are affected by bleeding disorders. Programming is provided in Spanish and is possible thanks to a grant from Shire. For more information, visit the HNC website.

Warren Jewett, a Life Well-Lived

It is with great sadness that we announce the passing of HNC member, Warren Jewett, Sc.D., on April 20, 2018. Warren, 87, lived with severe hemophilia A. Warren's passing again reminds us of all the unique, inspiring, and important stories that live within our community. As we look to the future—a future of promise and hope—we must remember our history: we wouldn't be where we are as a community without those who came before us. I encourage everyone to take an opportunity at future bleeding disorder events to look around, find someone you don't know, and strike up a conversation. It is amazing to think about all of the talented people within this community. Hear their stories, share yours, and remember that we are all in it together.

~ Charlene Cowell, HNC Executive Director

Warren's Obituary

Warren was born in Newton, Massachusetts on July 13, 1930. He was the second of three children born to Caroline Read Jewett and Abel Longley Jewett. His older brother, David, died at one year of age. As a young child, Warren moved with his parents and his younger sister, Pam, to Connecticut, and he was raised in the home his father built in Woodbridge. At age 12, he enrolled at Hopkins Grammar School in New Haven. While there, he discovered his love of Math and Science, and a beloved math teacher urged him to attend Brown University. He attended Brown from 1948-1951 and then transferred to the University of Arizona, where he studied Astronomy and spent time at the Lowell Observatory in Flagstaff. Several years later, he earned a Doctor of Science from the U.S. Naval Graduate Program.

Warren was born with severe hemophilia and throughout his life underwent too-numerous-to-count hospitalizations for treatment of bleeding episodes. To keep him occupied during these times, his father, himself an inventor and tinkerer, would bring him parts of clocks and radios to assemble. Warren emulated his father and developed a love for gadgets and keen ideas for improved designs. Coupled with his own experience with medical devices and their shortcomings, Warren's love of "building a better mouse trap" blossomed into his ultimate career as a biomedical engineer.

In 1952, Warren married Averell Barnes, and they had three children together. The family lived together in Connecticut, where Warren built a business designing biomedical instruments. In 1970, his company was purchased by Schick and became their biomedical division. In 1975, Warren accepted a position on the faculty of the University of Arizona in the Electrical Engineering Department, where he remained until 1985. He especially loved the collegial and mentoring relationships he experienced there.

In 1985, Warren married Brenda L. Plassman, Ph.D., and embarked on a new chapter of his life. They traveled extensively and lived in Australia for a time while Warren collaborated with colleagues on his many projects. In 1988, the couple settled in Cary, North Carolina. Over these past thirty years, Warren has engaged in numerous business ventures. He was the president of Sonodyne America Limited, an Australian-based biomedical engineering company. Later, he was the Chief Executive Officer of another biomedical company, IEP

Group, which was ultimately purchased by KOS Pharmaceuticals. Subsequently, he created numerous start-ups for the purpose of designing biomedical devices. A number of his more recent projects were founded to aid in the work of his wife, Brenda, a neuroscientist at Duke whose research focuses on Alzheimer disease. Warren holds numerous patents on his inventions, many of which are regularly used in medical settings today. Throughout his adult life, Warren devoted many years to advocacy for the hemophilia community, including serving as president of the National Hemophilia Foundation.

Warren lived life to its fullest despite physical limitations imposed by complications of hemophilia. He and Brenda shared their home with a young child (now adult), Natalya, and he enjoyed a second round of parenting. He was devoted to his family and routinely engaged with each individual on the topics most important to them. He assisted with numerous science fair projects (which he may have enjoyed more than his progeny!). He submitted to all manners of embellishment by his grandchildren, including face painting and manicures. He was generous beyond measure, always seeking to please loved ones. Favorite pastimes included spending time at Smith Mountain Lake, reading books of all sorts, and communing with dear friends. Dark chocolate, ice cream, and lobster were passions.

Warren leaves behind his wife, Brenda; his sister, Pamela Hitchcock (John, Ph.D.) and their sons, Christopher Hitchcock, Ph.D. (Ann Lindline) and Edward Hitchcock (Laura) and their children; his children, Tamison Jewett, M.D. (Jim Greenstreet), Keith Jewett (Maureen), and Jennifer Jewett (Patrice Mackey); nine grandchildren, Tyler Greenstreet, Cary Greenstreet, Hayley Greenstreet, Amanda Zekanis, Emma Jewett, Sofia Mackey, Isabel Mackey, Natalya Mangum, and Khalid Mangum, and 2 great grandchildren, Audrey and Avery Zekanis. Additionally, he leaves behind many members of Brenda's extended family, who also adored him.

The family asks that those interested in making gifts in Warren's honor consider donations to Hemophilia of North Carolina (www.hemophilia-nc.org/donate), Hopkins School (www.Hopkins.edu), or Christ the King Lutheran Church (www.christthekingcary.org/onlinegiving).



The life of a hemophiliac born in a developing country...

By: Ousmane T. Seck, HNC Member

My late brother was born almost 41 years ago with moderate Hemophilia B, the same year the Hemophilia of NC (HNC) chapter was founded. As many hemophiliacs he was a very active and energetic boy who would not let his condition or the risks associated with it slow him down. He never used his condition as an excuse, but rather overdid everything so not to be reminded he was different from his buddies. Pape Alboury Seck (he went by Papi being named after my grandfather) was born in Senegal, West-Africa, just 17 years after the country—a beautiful coastal and peaceful former French colony—gained independence with limited, yet decent infrastructures and healthcare facilities. He was likely the first documented hemophiliac to be formally diagnosed in the country due to uncontrollable bleeding following circumcision which is often customary due to cultural and religious beliefs. He is also my life hero and a model of resilience, optimism, and wisdom beyond his years.

Being born in a developing country in the seventies presented unique challenges in terms of services and access to quality healthcare, let alone being born with hemophilia B (or Christmas Disease). At the time the few hematologists in the country were European doctors working at the National Transfusion Center, and likely not well informed about hemophilia. I suspect this was the case worldwide considering the rarity of the condition, and to this day still a challenge in some parts of the world. Needless to say minor bleeds, tooth extractions, and minor trauma very quickly became major medical emergencies. Therefore patients who required advanced treatment, including my brother frequently had to travel abroad at their own family's expense. This is where the other hero in my life sprang into action. My mother, a practicing pharmacist, made contact with the French Hemophilia Association (AFH) and developed a life-long partnership that allowed us to attend their training sessions, summer camps, and most importantly access the same hospitals and treatment centers as French hemophiliacs. This came at a steep cost, my brother not being covered by France's social security system (akin to Universal Coverage or to a nationwide Medicaid system). He was initially



Ousmane was born in Senegal, West Africa and moved to the US in 2000 to attend the University of South Carolina in Columbia, SC. He spent most of his career in the Retail Pharmaceutical Industry and currently works as a Healthcare Project Manager with a major medical group in Charlotte, NC. He is married with two children and lives in Fort Mill, SC with his family.

treated with fresh plasma, then cryoprecipitate, and later anti-hemophilic factors that my mother had to order from France, arrange for international air crew to fly them over in coolers. Often she would fight bureaucratic red tape to have them admitted in the country as these were not officially approved treatments. Neither

my mum nor my brother ever complained about the cost of treatment, or the pain and inconvenience associated with these complex drugs, respectively. To the contrary, we all learned as much as possible about the condition and managed as best as we could, while my brother became an expert at home-infusion and palliative care (he made ice, bandages, and casts his daily tools), even wowing doctors and nurses with how much he knew about Hemophilia. My mother ensured he lived a normal life, went to the best schools she could afford, played sports (soccer, basketball) and wore the latest trends as he loved to dress up in those sports famous team gear. He lived to be 18 years old, beating all odds in that day and age, with only minor arthropathies and almost no deformities. He developed complications following abdominal surgery, slipped into a coma, then drifted away quietly on the morning of Sunday April 23, 1995.

When my brother passed away my mother answered the call to setup the Senegalese Hemophilia Association (ASH in French) in her words, so “No other child living with hemophilia dies unnecessarily in the country because of lack of proper diagnosis, access to quality care, or lack of adequately trained medical personnel.” She reached out to the French Hemophilia Association (AFH) and the World Federation of Hemophilia (WFH) for institutional support. The NMO was recognized in 1998 at the WFH Congress in the Netherlands, and started benefiting from their guidance and technical assistance, and clinical training opportunities to provide better care for hemophiliacs in Senegal while maintaining its traditional ties with AFH. The fight for better hemophilia care and access to treatment has always been a personal and moral issue in our family. Ten years ago my mother, my hero, stepped down as NMO President, insisting upon giving the management organization back to those living with Hemophilia

Continued next page

The life of a hemophiliac born in a developing country...

continued from previous page



Ousmane and his mother attend the World Federation of Hemophilia Congress in Orlando, FL, in 2016

and bleeding disorders. She is still very much involved in advocacy, fundraising, and advising the NMO staff. However she challenged all of us to face our personal responsibility to become much more involved as more hemophiliacs are diagnosed and need lifelong management and support. Now the organization is well established, with an IHTC housed within the National Transfusion Center, a team of qualified hematologists and other health professionals with solid diagnosis and disease management capabilities. Many challenges still exist: proper diagnosis, especially in remote areas, fundraising and sustainability, advocacy and training. Through donations from the WFH Humanitarian Aid Program, factors are now available but for how much longer? The government started purchasing factors a couple of months ago through the National Pharmacy but they are neither free nor subsidized, therefore inaccessible to patients. Efforts are undertaken to develop a system similar to the 340B Drug Pricing Program in the US.

In Africa there is a widespread saying that most of you have heard before, “It takes a village to raise a child”. You may have also heard in recent years that “blood thickens”. That is precisely the message I hope to convey to everyone reading this piece, we absolutely need to show unity and solidarity in building blood bridges across the globe, raising awareness about disparities within our own Hemophilia communities, and hopefully closing the gap through global cooperation and twinning programs to foster long-term partnerships among communities united by unbreakable blood ties.

Your dreams. Our dedication.

For over 60 years we have been inspired by people like you. We continue to work as tirelessly as we did in the very beginning, with unwavering focus on our ultimate goal: **a life full of dreams and free of bleeds.**

Shire

bleedingdisorders.com

Alex
Hemophilia A
Massachusetts

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HNC Advocacy Update



HNC's focus on advocacy continues to grow in 2018. For the first half of the year, the Advocacy Committee has been hard at work to support advocacy efforts around the state and throughout the country. Advocacy efforts so far this year include: participation in NHF's Washington Days; the Advocacy Panel Discussion about advocacy in the community at the HNC

Annual Meeting this past March, which emphasized the importance of advocating for bleeding disorders and other rare diseases; continuing to work with our national organizations on several issues impacting people throughout the country who live with a bleeding disorder; and gathering in Raleigh on June 14 for the HNC Legislative Day, where members of the community had a chance to meet with legislators in person to tell their story.

All of this is only possible with an active Advocacy Committee. For the Advocacy Committee to continue to grow and bring HNC member stories to lawmakers and other decision makers, the committee needs more community members to join in the effort.

The Advocacy Committee meets monthly via conference call, so no matter where you are in the state, you will have easy access to be part of a unified voice for HNC on behalf of people with bleeding disorders. You don't have to have any prior advocacy experience, members of the Advocacy Committee will help you to learn the ropes and understand the hot topics. The important thing is that you bring your story!

To join HNC's advocacy efforts, we encourage you to be proactive and participate on our monthly advocacy committee calls. You may also register for the advocacy committee email list for continuing updates about advocacy initiatives by emailing advocates-subscribe@hemophilia-nc.org or calling the HNC office at (800) 990-5557 to get involved!

Stay Connected to News about Bleeding Disorders

If you are interested in staying up to date on what's happening around the country and throughout the world of bleeding disorders, connect to Hemophilia Federation of America (HFA) and National Hemophilia Foundation (NHF) news systems.

HFA's News and Perspectives page of their website, www.hemophiliafed.org, provides information about community and medical news including drug safety information, fitness, advocacy, health care coverage, and more. For those who wish to stay connected, sign up for regular updates using

the link at the bottom of the page. Individuals can select the type and frequency of updates they'd like to receive.

NHF's Newsroom tab on their website, www.hemophilia.org, provides news articles on a variety of topics that include blood safety, industry, medical advisories, advocacy and legislative, and other subjects related to the community. Any members who wish to keep up to speed about everything bleeding disorders can sign up for the email newsletter(s) of their choice using the link for eNewsletter Sign Up on the NHF website.

MedicAlert ID and Membership Free to HNC Members



MedicAlert IDs can be a critical part of keeping someone with a bleeding disorder safe in cases of accidents, unexpected emergency room visits, and other unforeseen medical situations. A MedicAlert ID would alert a first responder or medical provider that a person has a bleeding disorder. Through the MedicAlert membership, these health care professionals would have access to a patient's medical diagnoses, prescriptions and medications, and allergies, so they can experience safer care. HNC can provide those diagnosed with a bleeding disorder an ID from www.medicalert.org priced up to \$35 along with the basic annual membership. Contact the HNC Office at (800) 990-5557 or email info@hemophilia-nc.org for more information.

Hemophilia of North Carolina 2018 Calendar of Events Highlights



July 20-22, 2018	Men's Retreat – Blowing Rock, NC
July 24, 2018	HOPE Dinner – Greenville, NC
July 28-29, 2018	Latin Union Retreat – Winston-Salem, NC
August 14, 2018	HOPE Educational Dinner – Charlotte, NC
August 19, 2018	Family Day Out – Tanglewood Park, Clemmons, NC
August 23, 2018	Educational Dinner – Raleigh, NC
September 15, 2018	HNC Family Festival & 5K Walk for Bleeding Disorders – Morrisville, NC
September 29, 2018	Blood Brotherhood Event – Lumberton, NC
October 19-21, 2018	Family Retreat – Concord, NC
October 24, 2018	HOPE Dinner – location TBD
November, 2018	Adult Retreat – Wilmington, NC
December 1, 2018	Holiday Celebration – Concord, NC
December 1, 2018	Latin Union Event – Concord, NC
December 15, 2018	Blood Brotherhood Event – Hickory, NC



Donate to HNC

Your support makes it possible for Hemophilia of North Carolina to continue its many programs and services to the bleeding disorders community. It means education for young parents, scholarship opportunities, financial assistance to families in crisis, and much more. *Your dollars make a difference.*

NAME: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

HOME PHONE: _____ CELL PHONE: _____

COMMENTS: _____

AMOUNT: _____

Please make checks payable to Hemophilia of North Carolina. We are a 501c(3) non-profit organization, so your donation will be tax deductible to the extent allowed by law. We will send you a receipt for tax purposes.

You may also donate online at www.hemophilia-nc.org with your credit card.

Thank you!





HEMOPHILIA OF NORTH CAROLINA

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Hemophilia of North Carolina

FAMILY '18 FESTIVAL

& 5K Walk for Bleeding Disorders

Saturday, September 15, 2018

Lake Crabtree County Park
1400 Aviation Parkway
Morrisville, NC

Check-ins begin at 9:00am

**Opening Announcements begin at 9:45am
followed by the Official Walk Start**

5K / 3.1 Miles or
2.4K / 1.5 Miles (short route)

save the date

START YOUR WALK TEAM TODAY!

- Join Hemophilia of North Carolina (HNC) for its annual Family Festival and 5K Walk, fundraisers dedicated to
- preventing the complications of bleeding disorders.
- All proceeds help us continue our education, advocacy, and peer support programs and services to our North Carolina community. Your support and participation ensures that the enthusiasm and impact of Hemophilia of North Carolina will make a difference across the state!
- For more information please visit:
- **www.hemophilia-nc.org/festival** or contact:
- **Gillian Schultz, HNC Program Manager**
- at **festival@hemophilia-nc.org**
- or call **(800) 990-5557**.

www.hemophilia-nc.org/festival